



## **Productivity Commission Inquiry into Data Availability and Use**

Response to the draft report from Cancer Council Australia

December 2016

**Cancer Council Australia** is Australia's peak national non-government cancer control organisation and advises the Australian Government and other bodies on evidence-based practices and policies to help prevent, detect and treat cancer and also advocates for the rights of cancer patients for best treatment and supportive care.

### **Overview**

Cancer Council Australia welcomes the opportunity to provide comment on the Commission's draft report on the public inquiry into data availability and use.

Cancer Council Australia agrees with the Commission that 'health data collection and use in Australia is scattered, unorganised and duplicative' and that 'government policies and practices must emphasise improved access to health data for both individuals and researchers, and improved data sharing between the participants in Australia's health system'. Cancer Council Australia believes that the implementation of a number of the recommendations outlined in the draft report will help ensure that opportunities to make greater use of collected health data in Australia are realised.

Areas in the draft report that were of particular interest to Cancer Council Australia included the case study on health data, specifically, the role of electronic health (e-Health) systems in improving health data collection and transfer (D.2 The development of eHealth in Australia), as well as opportunities to make better use of linked datasets (D.3 Using health data in research and policy development) and improve the availability and use of public health sector data (D.4 Improving the availability and use of health data). Comments on these areas are outlined below, in addition to Cancer Council Australia's response to a specific data request that was made in the draft report.

Cancer Council Australia looks forward to reading the Commission's final report.

## **Availability and use of public sector data**

In Australia, there are currently gaps in cancer data, where the data is either not available, incomplete, or not sufficient for national reporting purposes. There are specific gaps in health services and expenditure data, and more information is required in order to develop a better understanding of what services are being delivered, how effective they are, and where money is spent. There is also a lack of data relating to patient experiences of care within health services. With advances in prevention, screening and treatment, many of those affected by cancer are now living longer, either free of disease or with recurrent disease. Despite this, there is little data describing the quality of life of patients after treatment, intermediate and long-term toxicities, or the impact of new treatments and technologies.

Improvements in the completeness, quality and availability of cancer data, particularly for the purposes of research, will help strengthen the evidence base on emerging cancer issues, current and planned cancer control interventions, and future trends.

As outlined in our submission to the Inquiry, there are a number of factors that are currently preventing government agencies from making their data available, including:

- government attitudes and legislation that assume the community would be opposed to greater sharing and use of personal data for research, without any evidence that this is the case
- legislative, logistic and other administrative problems in transferring and exchanging data between states and territories
- internal agency and government culture and policies that have developed over time, that place unnecessary and cumbersome restrictions on the release of data
- lack of funding for, and failure to prioritise, the development of advanced data systems and infrastructure

Cancer Council Australia believes that the implementation of recommendations in the draft report, particularly those focused on addressing specific impediments to public sector data access (recommendations 3.1, 3.2), making data more useful (recommendation 6.1) and valuing and pricing data (recommendations 7.1 – 7.4), will begin to address a number of the barriers outlined above, including for researchers working in the health and medical research sector. The concept of 'trusted users' is particularly significant as a research enabling function, as this is where we see researchers positioned in the proposed new data framework.

## **Linked datasets**

Cancer Council Australia's submission to the Inquiry highlighted a number of high value cancer datasets, which when linked, will enable better informed health policies and service delivery and more efficient use of health resources. The submission also identified a number of barriers to the linking of multiple health datasets in Australia (including legislative barriers to data access and concerns regarding the protection of individuals' privacy), and indicated that there would be benefits in harmonising Commonwealth and State and Territory legislation in relation to privacy.

As outlined in our submission to the Inquiry, well-established data linkage protocols that are capable of preserving individual privacy already exist in Australia. Cancer Council Australia believes it is critical that government continues to invest in initiatives such as the Population Health Research Network (PHRN), which is developing and testing leading-edge technology to ensure the safe and secure linking of data collections whilst working to protect peoples' identity and privacy. One such example that is described in the draft report is the Secure Unified Research Environment (SURE) system, a remote-access data research laboratory developed by the Sax Institute as part of the PHRN, that enables structured access for researchers to secure and sensitive datasets held on separate secure servers<sup>1</sup>.

Cancer Council Australia believes that the implementation of recommendations 5.1 – 5.5 in the draft report will help to address a number of the current barriers to data linkage in Australia.

Please see below Cancer Council Australia's response to the draft report's information request on linked datasets.

### *Information request*

The Commission seeks further views on the most practical ways to ensure improvements to linked datasets are available for subsequent dataset uses.

### *Cancer Council Australia's response*

With regard to publicly funded data, it is important that the investment in value adding through data linkage be used in further research, rather than be wasted. Linked data should be preserved for use in further research where:

- there is human research ethics committee (HREC) approval for this further research; and
- there is source data custodian approval for this further research.

Where the original linked data were placed in the SURE system, the Sax Institute or the Australian Institute of Health and Welfare (AIHW) could be responsible for storing the data for further use. Where the data were linked and used at a jurisdictional level only, the respective jurisdictions should be responsible for storing the linked data. A mechanism for jurisdictional storage should be developed by each jurisdiction with approval of a relevant duly recognised HREC.

## **Electronic health (e-health) systems**

Cancer Council Australia's submission to the Inquiry outlined the key benefits of personally controlled electronic health records (PCEHRs), particularly in the area of cancer care, where best practice care is delivered by a multi-disciplinary team, and the use of PCEHRs can facilitate the sharing of patient data across different healthcare providers and organisations.

Our submission noted that while PCEHRs can help consumers become more proactive participants in the management of their own health, and facilitate improved consumer-provider communication and access to data in medical emergencies, there are also a number of challenges. As noted in the draft report, there has been much debate regarding the level of individuals' control over the information contained in their My Health Record. Individuals are able to remove clinical or Medicare documents from their My Health Record at any time, and as a result these documents may no longer be accessible, even in an emergency. If individuals remove information without consulting with the relevant healthcare professional(s), this raises concerns about the accuracy and reliability of the data contained within the record.

During the June 2016 release of the updated Australian Medical Association (AMA) *Position Statement on Shared Electronic Medical Records*, AMA president Michael Gannon noted that 'Shared electronic medical records have the potential to deliver huge benefits by giving health workers ready access to critical patient information when it is needed, reducing the chances of adverse or unwarranted treatments and improving the coordination of care. But, if patients are able to control access to core clinical information in their electronic medical record, doctors cannot rely on it. Giving patients such control, as the My Health Record system does, is a big handicap to the clinical usefulness of shared electronic medical records'<sup>2</sup>. Notably, the World Health Organization's 'Atlas of eHealth country profiles 2015' released in February 2016, shows that in approximately 70-80% of countries that have, or are working towards the implementation of an e-health record system, patients do not or will not have access to or content control of their e-health record<sup>3</sup>.

Cancer Council Australia believes that individuals should have a Comprehensive Right to access digitally held data about themselves, including the right to request edits or corrections for reasons of accuracy (as detailed in recommendation 9.2 in the draft report); however, serious consideration needs to be given to the level of content control patients currently have with regard to the My Health Record, as it is likely to have an impact on how the record is viewed by healthcare professionals, and as a consequence its utility in clinical practice and its value to health and medical research.

## References

1. Sax Institute. Secure Unified Research Environment (SURE). Available at: <https://www.saxinstitute.org.au/our-work/sure/>
2. Australian Medical Association. Media Release: *Access to core information critical to e-Health record success*. 16 June 2016. Available at: <https://ama.com.au/media/access-core-information-critical-e-health-record-success>
3. World Health Organization. *Atlas of eHealth country profiles: the use of eHealth in support of universal health coverage: based on the findings of the third global survey on eHealth 2015*. Geneva: WHO; 2016. Available at: [http://www.who.int/goe/publications/atlas\\_2015/en/](http://www.who.int/goe/publications/atlas_2015/en/)